

Compensating Patient Partners in Research:

Review of Current Guidance and Policies Across Canada



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Public and Patient Engagement Collaborative

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The issue of compensating patient partners is a challenging area with many factors to consider. Some of these considerations include determining different forms and levels of payment for different roles, distinguishing between compensation and the coverage of expenses, and how to navigate these important discussions and decisions within research teams.

These considerations when paying patient partners in research are discussed in detail on the [Canadian Institutes of Health Research \(CIHR\) website](#).

To complement this guidance, we have summarized the various compensation policies across the SPOR SUPPORT Units in Canada and provided links to additional compensation resources to inform these important discussions and decisions within research teams.

Note: The information shared below was retrieved from publicly accessible resources in August 2023

Table 1: High-Level Summary of SPOR SUPPORT Unit Patient Partner Compensation Policies

Activity	Level of Commitment	Examples	Suggested Compensation	Considerations
<u>One-time Activity</u>	One-time commitment, plus any preparation required	Planning and/or priority setting meetings, workshops, speaking engagements (podium or panel), reviews, research activities, etc.	\$25/ hour¹ <u>or</u> Half-day rate (+/- 4hrs): \$50 – \$100² Full-day rate (+/- 8hrs): \$75 – \$200	Meeting prep time should be recognized by honorarium and combined with the meeting time. Costs may need to be adapted for specific populations and communities (see Knowledge Keepers). An honorarium offered will depend on the level of time and complexity of the activity as well as the effort and skill level required.
<u>Council or Working Group</u>	On-going commitment to a committee or group (includes meetings, follow-up actions, etc.)	Membership in a working group, standing committee, patient advisory council, etc.	\$200 to \$1500 per year³ , depending on frequency of meetings and volume of independent work outside of meetings	Compensation for participation in meetings only ranges from \$100 to \$400 (e.g., \$50 per meeting). More time intensive commitments that pair meetings with additional one-time activities require higher compensation (i.e., working group that meets 6 times, for 2 hours, participating in other events, reviewing documents, and small presentations = \$1500).

¹ Alberta (AbSPORU) and Ontario (OSSU): \$25/hour; Quebec (SSA Quebec): \$22.82 to \$50/hour (up to \$250 max).

² AbSPORU: \$100 for half-day, \$200 for full-day; SK (SCPOR) and NL (NL SUPPORT): \$50 for half-day, \$100 for full-day; Maritime (MSSU): \$25 - \$50 for half-day, \$50 - \$100 for full-day.

³ SCPOR: \$100 - \$200/year (less than 4 meetings), \$200 - \$400/year (more than 4 meetings); MSSU: \$100 - \$300/year (less than 8 meetings), \$300 - \$400/year (between 8 and 12 meetings); NL SUPPORT: \$200/year (3 to 4 meetings); OSSU Patient Partner Working Groups: \$1500/year, \$2000/year for Vice Chair, \$2500/year for Chair.

Knowledge Keepers		Land acknowledgement, ceremonies, participation, etc.	Half-day rate (+/- 4hrs): \$200⁴ Full-day rate (+/- 4hrs): \$400	Any guidelines may have to be adapted to cover expenses for unique populations and communities, including Indigenous Elders and Knowledge Keepers.
Expenses Reimbursing expenses does not fit the definition of compensation.				
Coverage	Travel (including mileage, parking, airport transport, etc.) Accommodations (if out-of-town) Meals per diem (if out-of-town) 3 hours of travel time (\$25/hour) for those who spend the day before or after a meeting travelling. Dependent care allowance (e.g., childcare, elder care, family with differing abilities). Reimbursed up to \$100 per day (with an invoice) or up to \$50 per day (without an invoice). Any other expenses incurred related to the engagement (e.g., long-distance phone charges).		Costs should be paid upfront by the research team as much as possible , rather than burdening the patient partner with the outlay of funds or added work of submitting an expense claim.	

⁴ Rates per SCPOR, but acknowledgment of varying rate for Knowledge Keepers/Indigenous Elders by AbSPORU and NL SUPPORT.
Table structure adapted from: [Canadian Institutes of Health Research – Institute of Genetics: Patient Partner Compensation Guidelines](#)

Table 2: Detailed Summary of SPOR SUPPORT Unit Patient Partner Compensation Policies

	<u>BC</u> BC SUPPORT Unit	<u>AB</u> AbSPORU	<u>SK</u> SCPOR	<u>ON</u> OSSU	<u>QC</u> SSA Quebec	<u>NB, NS, & PEI</u> MSSU	<u>NL</u> NL SUPPORT	SPOR Evidence Alliance*
Type of Comp.	<i>Patient Partner Appreciation Guide currently in-progress (anticipated publication Winter 2023)</i>	Fixed Service Income (hourly) and Honoraria (lump sum)	Honoraria	Fixed Service Income and Honoraria <i>Note: OSSU will negotiate with individual patients on the form of compensation</i>	Fixed Service	Honoraria	Honoraria	Payment Rates: <i>Fixed Service Income</i> (hourly or daily rate) or <i>Honoraria (one-time lump sum payment</i> for attending an event or for participating in a short- term activity) Payment Type: <i>Cash</i> (cheques or gift cards) or <i>In-Kind Payment/Gifts</i> (e.g., free access to a resource, conference registration fees, etc.)
Patient Partner Roles		<u>Option 1:</u> A one-time request to collaborate. <u>Option 2:</u> Member of working group, advisory council, or committee. <u>Option 3:</u> Partner on research project or activity	SCPOR/SHA committees or working groups SCPOR funded programs Education or awareness events	Planning and/or priority setting meetings Workshops Speaking engagements (podium or panel) Reviews Patient Partner Working Groups (PPWG)	Governance Development of research priorities Research team member Education	Working Group Standing committee MSSU-led research team Any other event where compensation is offered	<u>Option 1:</u> Patient Advisory Council meetings and/or Indigenous Council meetings. <u>Option 2:</u> Reviewing funding applications, and being part of a working group, core component committee, steering committee, oversight committee,	See below

							events and/or funding applications. <u>Option 3:</u> Recruitment for skill set or a specific task not described (e.g., patient co-facilitator).	
Amount		<p>Option 1 Hourly rate: \$25h Half-day rate (+/- 4hrs): \$100 Full-day rate (+/- 8hrs): \$200</p> <p>Option 2 Less than 4 meetings per year: \$100 to \$200 More than 4 meetings per year: \$200 to \$400</p> <p>Option 3 Refer to rates in <i>Option 2</i> for standing collaborations and <i>Option 1</i> for one-time consultations or active collaboration.</p>	<p>Honoraria Less than 2h: \$25 2 to 4h: \$50 More than 4h: \$100</p> <p>Knowledge Keepers Half-day rate: \$200 Full-day rate: \$400</p>	<p>Work Outside PPWG Hourly Rate: \$25h</p> <p>PPWG Annual (per year/member): \$1,500</p> <p>Annual – Chair: \$2,500 Annual – Vice Chair: \$2,000</p> <p>Additional work beyond outlined scope: \$25h (up to \$300 max)</p>	<p>Suggested Hourly rate: \$22.82 to \$50h (up to \$250 max)</p>	<p>Honoraria One-time engagement (less than 4hrs): \$25 to \$50 One-time engagement (4 to 5h): \$50 to \$75 One-time engagement (8h): \$75 to \$100 Standing committee or working group (8 to 12 meetings per year): \$300 to \$400 Standing committee or working group (less than 8 meetings per year): \$100 to \$300</p>	<p>Option 1 Annual (per year/member): \$200</p> <p>Option 2 Half-day (up to 3 h): \$50 Full-day (more than 3h): \$100</p> <p>Max \$300 per year</p> <p>Option 3 Discuss the most appropriate form of appreciation – could include a flat rate per day, contractual arrangements, or culturally appropriate appreciation.</p>	<p>Fixed Service Income Meeting, Document Review or Advisory: \$25h</p> <p>Project-Based Work: \$25h</p> <p>Honoraria Presentation or Panel/Facilitation: To be determined by the activity leader based on the extent of time and effort required.</p> <p>External Events: \$100 half day (3-4h) \$200 full day (7-8h)</p>
Eligible Expenses		Travel Parking Caregiving	Meals per diem: Breakfast - \$10.00 Lunch - \$18.00 Supper - \$23.00	Policy 230 - OSSU Travel Expenses Reimbursement Guidelines – not available online.	Travel Accommodation Meals	Transportation Meals (per diem rates determined by the host institution)	Travel Accommodation Meals per diem	Transportation Accommodation (if out-of-town)

	<p>Digital Access</p> <p>Training</p> <p>Any other direct costs or expenses associated with engaging.</p> <p>Costs should be paid upfront by the research team as much as possible, rather than burdening the patient partner with the outlay of funds or added work of submitting an expense claim.</p>	<p>Parking Expenses</p> <p>Hotel Expenses</p> <p>Mileage</p>		<p>Conference Fees</p>	<p>Accommodation</p> <p>Additional costs will be considered on a case-by-case basis (e.g., childcare, eldercare).</p> <p>Eligible expenses incurred by a patient partner will be reimbursed following the host institution's rates and processes.</p>	<p>Any other expenses incurred by patients when attending meetings.</p>	<p>Meals per diem (if out-of-town)</p> <p>3 hours of travel time (\$25h) for patient partners who spend the day before or after a meeting travelling.</p> <p>Dependent care allowance (e.g., childcare, elder care, family with differing abilities): Reimbursed up to \$100 per day (with an invoice) or up to \$50 per day (without an invoice).</p> <p>Any other expenses incurred related to the engagement (e.g., long-distance phone charges).</p> <p>Reimbursing expenses does not fit the definition of compensation.</p>
Other	<p>It is essential that compensation is offered for pre-meeting activities such as reviewing agendas, documents and for time providing feedback through email communication.</p>	<p>Meeting prep time will be recognized by honorarium and will be combined with the meeting time.</p> <p>Honoraria is not provided for travel time, orientation, or other education events that patient</p>	<p>Scope of Yearly PPWG Activities:</p> <p>Business meetings (6 x 1.5hrs + prep time)</p> <p>Participation on specific OSSU working groups.</p> <p>Review EMPOWER applications</p>		<p>To determine the amount within this range, consider the following: level of responsibility, preparation time, public speaking request, or a higher level of responsibility; or are other means of appreciation being</p>	<p>Honorarium offered will depend on the level of time and complexity of the engagement opportunity as well as the effort and skill level required of the patient partner.</p>	<p>Participation in SPOR Evidence Alliance Events is not eligible for compensation (unless presenting or facilitating)</p> <p>Costs may need to be adapted for specific populations and communities.</p>

		These guidelines may have to be adapted to cover expenses for unique populations and communities including Indigenous Elders and Knowledge Keepers.	partners are not required to attend.	Other small projects presented in <i>Annual Workplan</i>		offered (for example, if a registration fee is being covered). Participation in the annual workshop or MSSU event is not eligible for compensation (unless presenting or facilitating)		Patient partners are responsible for tracking and claiming their own hours. Form can be found on page 7 of the reference document (see below).
URL		Patient Partner Appreciation Guidelines: Compensation in Research (February 2023)	Patient Partner Honoraria (2021) Honoraria & Expenses (2021)		Principes directeurs: Dédommagement financier pour la recherche en partenariat avec les patients et le public (May 2018)	Patient Partner Compensation and Reimbursement Policy (May 2020)	Patient Partner Appreciation (March 2023)	Patient Partner Appreciation Policy and Protocol (August 2022)

* Although not a SPOR SUPPORT Unit, the SPOR Evidence Alliance compensation standards inform many of policies listed in Table 2.

** No information available for George & Fay Yee Centre for Healthcare Innovation (Manitoba), Northwest Territories SPOR SUPPORT Unit (Hotii ts'eeda), Yukon SPOR Unit, or Nunavut

Table structure adapted from: [SPOR Networks in Chronic Diseases and the PICHI Network \(2018\). Recommendations on Patient Engagement and Compensation](#)

Additional Resources

SPOR Networks

- Can-SOLVE CKD: [Patient Council \(PC\) Overview of Terms and Conditions](#) (October 2017)
- CHILD-BRIGHT Network: [Guidelines for Patient-Partner Compensation and Recognition](#) (October 2022)
- Diabetes Action Canada: [Financial Compensation Policy for Patient Partners](#) (March 2023)
- IMAGINE Chronic Disease Network: [Financial Compensation Policy for Patient Representatives](#) (2021)

*** No relevant data for ACCESS Open Minds or SPOR Primary Care Research Network (Canadian Primary Care Research Network; Primary and Integrated Health Care Innovations Network)*

Canadian Institutes of Health Research

- CIHR-Institute of Genetics: [Patient Partner Compensation Guidelines](#) (2022)
- CIHR-Institute of Musculoskeletal Health and Arthritis (IMHA): [IMHA Patient Compensation Guideline](#) (2023)
- Strategy for Patient-Oriented Research (SPOR): [Considerations When Paying Patient Partners in Research](#) (2022)

International Health Research Institutes

- Patient-Centered Outcomes Research Institute (PCORI): [Budgeting for Engagement Activities](#) (2020)
- Patient-Centered Outcomes Research Institute (PCORI): [Engagement Rubric for Applicants](#) (2016)
- Patient-Centered Outcomes Research Institute (PCORI): [Financial Compensation of Patients, Caregivers, and Patient/Caregiver Organizations Engaged in PCORI-Funded Research as Engaged Research Partners](#) (2015)
- National Institute for Health and Care Research (NIHR): [Payment Guidance for Researchers and Professionals](#) (2023)
- National Institute for Health and Care Research (NIHR): [Public Contributor Payment Policy](#) (2022)
- National Institute for Health and Care Research (NIHR): [Payment Guidance for Members of the Public Considering Involvement in Research](#) (2023)